

In Sickness and In Health: Social Support and Inflammatory Bowel Disease

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of Science in Psychology

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Abstract

Crohn's Disease and Ulcerative Colitis, known collectively as Inflammatory Bowel Disease (IBD), are highly debilitating conditions which affect approximately 15,000 New Zealanders. The aim of the current study was to investigate factors which potentially influence the disease course of IBD such as life stress, depressive symptoms and social support. 60 participants (46 with CD and 14 with UC) completed an online questionnaire on measures of disease severity, stress, mental health, quality of life and social support. Participants with lower perceived social support ($r = -.398$, $p < .01$), higher stress ($r = .292$, $p < .05$), higher depressive symptoms ($r = .287$, $r = .330$, $p < .05$), higher anxiety symptoms ($r = .289$, $p < .05$) and lower quality of life ($r = -.302$, $p < .05$) had higher disease severity. Results failed to support a moderation relationship between social support and either stress and illness severity or depressive symptoms and illness severity. Results suggest perceived social support, stress and mental health are important treatment considerations, in addition moderate rates of mental health symptoms were reported by the sample highlighting the importance managing IBD in a biopsychosocial context.

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In Sickness and in Health: Social Support and Inflammatory Bowel Disease

Health psychology has long been intrigued by the potential moderating and mediating factors which influence the course of chronic illness like inflammatory bowel disease (IBD). This may be due to the huge social cost associated with chronic illnesses, Uchino (2009) reviewed the links between social support and psychical health, and highlighted that chronic diseases are the leading cause of mortality in most Western countries today. Recent studies note the rise in incidences of IBD in the West (Gearry et al, 2006) and the increased risk of mortality in those diagnosed (Card, Hubbard & Logan, 2003). One area of focus in the health psychology literature has been the role of social support. How does the way in which individuals receive, perceive and utilize social support affect our experience, adjustment and management of chronic illness?

Inflammatory Bowel Disease Overview

Crohn's disease (CD) and ulcerative colitis (UC) are chronic inflammatory illnesses of the intestines (Gearry, 2006; McCombie, Mulder & Gearry, 2013). These diseases, along with other less common forms, are collectively referred to as inflammatory bowel disease (IBD). As the cause or causes of IBD remain to be identified, CD and UC are defined by their clinical features. CD and UC can be distinguished from each other by the area of the body which is affected; CD can occur in any part of the digestive tract, whereas UC only affects the large intestine (Ministry of Health, 2013). The onset of IBD is typically during adolescence and commonly involves acute abdominal pain, diarrhoea, rectal bleeding, nausea, fever, fatigue and weight loss in the acute phase (Gerry et al, 2006; Matini & Ogden, 2015). Even patients who achieve remission can continue to experience problems like fatigue (Matini & Ogden, 2015).

The causes of IBD are the subject of extensive research with many aetiologies being posited, including genetic and environmental factors (Gearry et al, 2006; Baumgart & Carding, 2007). Environmental factors that have been implicated include smoking, reduced rates of breastfeeding, western diet, and antibiotic usage (see Baumgart & Carding, 2007 for a review). Despite the large body of literature no single conclusion has been drawn. Additionally, many factors are posited to influence the course of IBD, such as smoking, certain foods and beverages, exposure to stress and mental health (Gearry et al, 2006). The disease typically follows a relapsing-remitting course, wherein patients go through periods of disease activity and remission. Therefore, it would be beneficial for sufferers to know factors that may influence or protect against a relapse in symptoms, and whether it is possible to influence these factors. Psychosocial factors such as stress, personality and mental health have been the subject of research in this field, having first been reported in 1930 (Maunder, 2005). Maunder reports that these factors, particularly stress, may be more relevant for IBD than any other medical conditions, with 74% of patients reporting that stress contributes to the course of their disease (Maunder, 2005). Understanding the relationship between stress and IBD activity, and the potential moderating factors such as social support, may lead to new targets for treatment and a greater understanding of the disease.

Social Support

Defining social support. In the area of health psychology one topic of interest has been how stress and social support affect the onset and course of chronic illnesses (Adler & Matthews, 1994; Thoits, 2011). There have been many attempts to define social support. One definition states that social support is comprised of the following components: expression of positive affect; positive reinforcement of a person's beliefs, interpretations and feelings; encouragement to express beliefs; provision of practical aid; and providing the sense of being part of a network of support and mutual obligation (Sanders & Suls, 1982). Many key

terms and definitions of various types of social relationships have been suggested. Heaney and Isreal (2008) define a 'social network' as a web of relationships, which the individual develops over a lifetime. These networks may provide social support as well as other functions; such as resources and financial aid. House (1981) proposed that social support is the "functional content", meaning the active role of one's social network, and can be separated into four broad areas; emotional, instrumental, informational and appraisal support. Emotional support is the offering or receiving of love, trust, acceptance and empathy. Instrumental support is sometimes called tangible support and is the provision of practical facets or needs such as material goods or deeds. Informational support is the giving of advice, knowledge or other information to assist in problem solving or transitions. Appraisal support involves information by which people can engage in self-evaluation such as criticism, affirmation and normalisation. Other literature building upon House's (1980) concepts add companionship support as a fifth aspect of social support (Uchino, 2006). Companionship support fosters a sense of belonging or social connectedness, often through spending time as part of a group or pair.

Despite being able to conceptually separate the aspects of social support, empirically it has proven difficult to measure them separately; therefore social support is often studied as a single construct (Heaney & Isreal, 2008). However, as has been highlighted the concept of social support is broad with no single definition. This may lead to differences between studies due to how they interpret and define social support.

Social support and physical health. Research has suggested a relationship between social support, morbidity and mortality. Berkman and Syme (1979) conducted a landmark epidemiological study in which almost 7,000 American citizens living in California were followed over nine years. The results of their study showed that those who were more socially isolated had higher rates of mortality, and social support was predictive of a longer

lifespan (2.8 years for women and 2.3 years for men) even when controlling for factors such as health habits and socioeconomic status. Of interest was the finding that social support was a predictor of health outcomes, and in some cases a stronger predictor than common risk factors such as smoking and protective factors such as exercise. In another influential study Cohen and colleagues (1997) demonstrated that social support may influence acute illnesses also, they exposed 276 healthy volunteers (125 male, 151 female) aged 18 to 55 to the cold or flu virus and found those with more social networks were less susceptible to getting sick than those with fewer social networks, and those with lower levels of stress were also less susceptible. In addition, they found a dose-response relationship between number of social networks and susceptibility.

Berkman and Syme's findings have been replicated more recently; Brummett and colleagues (2001) examined social isolation as a predictor of mortality in 430 patients with Coronary Artery Disease (CAD). They found that those with smaller or non-existent social networks had a higher risk (2.4 times higher) of mortality; this finding was not attributable to confounding factors such as disease severity, distress or socioeconomic status. A meta-analysis of the literature on the relationship between social support and mortality risk reviewed 148 studies (Holt-Lunstad, Smith & Layton, 2010) and found a 50% increased likelihood of survival with positive social relationships across a variety of diseases including cancer and cardio-vascular disease (Odds Ratio [OR] = 1.5). Age, gender, initial health status, cause of death and length of follow up period were not found to be confounding factors. However, the way social support was measured was related to outcome with more complex measures finding stronger effects. The authors highlight that the effect size for social support is comparable to other health risk factors such as smoking and alcohol use, and even higher than those found for physical inactivity and obesity. Another review looked at the interaction between social relationships and health from a social policy point of view and concluded that

due to the consistent evidence of a relationship between social isolation and poor health outcomes social policy directed in this area would be beneficial (Umberson & Montez, 2010).

Research in this area has found support for a positive relationship between social support and various physical illness or medical processes, not just mortality rates (Umberson & Montez, 2010; Taylor, 2011; Thoits, 2011). Findings indicate a relationship between social support and better adjustment to and coping with chronic illness such as cancer, coronary heart disease HIV, rheumatoid arthritis, kidney disease, childhood leukaemia, and stroke though positively impacting mood, emotions and cognitive processing of events (see for a review Uchino, 2006). The natural question following the establishment of this finding was how does social support influences health outcomes, or put another way, what are the underlying casual mechanisms?

Models/mechanisms of social support. The theoretical underpinnings of social support have been a focus in health psychology research since two pivotal reviews in 1976 (Cassell, 1976; Cobb, 1976). Early causal explanations focused on the behavioural aspect of social support, the encouragement of healthy habits and lifestyle as well as the relationship between social isolation and stress (Umberson & Montez, 2010). The behavioural pathway includes the influence of social support on health behaviours and adherence, such as adherence to medication or treatment programs, diet and exercise; this in turn can have a direct or indirect impact on biological processes, and disease morbidity and mortality. The other proposed pathway involves psychological aspects such as appraisal, emotions or affect, and level of perceived control.

Uchino (2006) highlights that these pathways may not work independently of each other, and reports there is much evidence of behavioural and psychological processes being interlinked. In addition it is noted that there can be a reciprocal influence back onto social

support from these pathways. Uchino (2006) gives the example of distress influencing the perception of social support and thereby creating negative interpersonal interactions. The proposal of a feedback loop is important because it suggests that those with illnesses which have the possibility to affect the individual's social network may face additional challenges, as their social relationships may be negatively impacted due to the presence of the illness (e.g. the individuals cognitive perceptions of the received support). However research has suggested that the effects of social support go beyond the behavioural and psychological and have an impact at the physical level (Umberson & Montez, 2010). This led to a focus on posited physiological, neuroendocrine and immunologic processes to explain the interaction between social support and physical disease outcomes (Uchino, Cacioppo and Kiecolt-Glaser, 1996; Uchino, 2006).

Due to the diversity in illnesses found to be influenced by social support, there may be many casual pathways and these may be unique to each illness. The posited immune system pathway is particularly relevant to the scope of this review as IBD is an autoimmune condition, meaning the immune system is dysfunctional and damages healthy cells. Positive social support has been correlated with increased immune functioning in a number of studies (Dixon et al., 2001; Esterling, Kiecolt-Glaser & Glaser, 1996; Lutgendorf et al, 2005; Miyazaki et al, 2005) and has been found to have an influence on natural killer cell activity in patients with cancer and helper T-cell activity in HIV positive men (Lutgendorf et al, 2005; Levy et al, 1990; Person et al, 1994; Theorell et al, 1995). In their 1996 review Uchino and colleagues cited 19 studies which supported higher levels of social support being correlated with better immune functioning. Further to this they looked at the specific role of emotional support in immune functioning measured by four studies in their review. A meta-analysis of these studies showed a significant combined z score with a small effect size, suggesting that emotional support may have a mild effect on immune functioning and is therefore an

important part of social support. Uchino (2006) revisited this area in a later review and again concluded that immune function may be a pathway through which social support influences physical health.

Stress is proposed to play a role in the pathway between social support and immune functioning. Stress suppresses the immune system (through increased corticosteroids) and leaves a person vulnerable to disease and infection (McEwen & Stellar, 1993), as social support has a buffering effect against stress this may then protect against immunosuppression. However it is important to note that this model may not be relevant for autoimmune diseases like IBD which involve excessive inflammation (Taylor, 2007). Miller, Cohen and Ritchey (2002) developed a model which attempts to explain the negative impact of stress on excessive inflammation. They propose that chronic stress reduces the sensitivity of the immune system to glucocorticoid hormones, which turn off the “inflammatory cascade” that occurs when exposed to stress (increased inflammation). They compared 25 parents of children with cancer with 25 parents of healthy children and found the parents who were exposed to a significant stressor (child diagnosed with cancer) and reported higher levels of social support were found to have higher glucocorticoid sensitivity, and therefore more normal inflammatory reactions.

Another finding, which is directly relevant to IBD, is that social connectedness may have a negative effect on levels of C-reactive protein (reducing levels) which is a common marker of inflammation often seen elevated in IBD. Loucks and colleagues (2005) conducted a longitudinal study with 380 men and 425 women aged between 70 and 79 years. Their aim was to assess whether social integration (defined as number of social and interpersonal relationships) had an association with inflammatory risk factors of coronary heart disease, of which C-reactive protein was one. They found a significant inverse relationship between social integration and C-reactive protein in men only. Both of these studies indicate that a

relationship between social support and inflammation is present, wherein higher levels of social support are beneficial in moderating the illnesses inflammatory response to high stress levels.

Main effect vs the buffering hypothesis. Two theories have been suggested to explain the effects of social support; the main effect theory and the protective buffering theory. The main effect theory posits that social support promotes positive health outcomes directly under every circumstance (Camara et al, 2011). The buffering hypothesis suggests that the relationship between social support and health is moderated by stress as social support acts as a protective factor, meaning those who can use social support as a coping resource are more resistant to the negative effects of stressful life events (Schawrzner & Leppin, 1991). Cohen and Wills (1985) looked at the evidence for each theory and concluded that there was evidence for both models, but they represent different processes. The buffering hypothesis is evidenced when, after a stressful life event, the receiver of social support evaluates the perceived response. This type of support is most relevant in the context of IBD as the disease represents a significant life stressor.

Kawachi and Berkman (2001) suggest the models are not wholly independent, but may in fact represent different processes, with the main effect hypothesis representing the structural characteristics (e.g., structure of social network) of social support and the buffering hypothesis representing the functional aspects (e.g., the practical support). Meaning that the buffering hypothesis may be more relevant to the relationship between social support and physical health as it represents a functional process.

Perceived vs received social support. One of the sub-constructs that has been conceptualised in the social support literature is ‘perceived social support’ and ‘received social support’ (Haber, Cohen, Lucas & Baltes, 2007). Received support is defined as the

specific behaviour that the person receives from their support network, that is, what actually occurs. Whereas perceived support is defined as the person's perception of the availability of support or the satisfaction with provided support. Said another way it's the person's cognitive interpretation of the supportive actions of others and as such it is vulnerable to bias and is subjective. Some authors suggest that only perceived support has been consistently linked to physical health; however this hasn't yet been reliably established (Uchino, 2009; Haber et al, 2007; Barrera, 1986; Dunkel, Schetter & Bennett, 1990; Sarason, Sarason & Pierce, 1990; DiMatteo, 2004). This could be because the presence of support may only be beneficial if the receiver interprets it in a favourable manner. Meaning that support which is seen as negative by the patient could have a negative or no effect. This suggests that research that measures the mere presence of support as may lead to misleading results, as the support could be present and having a negative effect. Therefore it is important for research in this area to assess participant's perception of social support and the effect this has on illness outcomes.

Types of social support: Active engagement, protective buffering and overprotection. The ways in which a patient receives support from their significant other has been found to have a relationship with adjustment and coping processes such as the development of self-efficacy, which can impact a patient's health related behaviours such as medicine adherence, diet and physical activity (Coyne & Smith, 1994). Coyne and Smith's (1991; 1994) research indicates the ways in which support people interact with a person recovering from a myocardial infarction is related to a decrease in the patient's self-efficacy and an increase in the supporter's distress. The researchers propose that there are three ways in which a significant others interact with a patient (Coyne, Ellard & Smith, 1990; Coyne & Smith 1991; 1994). Active engagement refers to interacting in a way which is collaborative, involves both partners equally, and results in constructive problem solving. Active engagement has been found to be positively correlated to marital satisfaction, improvements

in the marital relationship post diagnosis (Hagedoorn, Kuijer, Wobbes & Sanderman, 2000), and higher patient self-efficacy and lower spousal distress (Coyne & Smith, 1991; 1994). Cancer patients interacted differently with their medical professionals depending on which type of support they received from their spouses, reporting less physical discomfort with active engagement (Heins, Hopman, Korevaar, Schellevis, Donker & Rijken, 2015). Couples coping with diabetes reported higher relationship satisfaction when support was given in an active engagement manner as compared to a protective buffering (see definition below) manner (Schokker et al, 2010). Furthermore the authors found that active engagement moderated the negative relationship between protective buffering and relationship satisfaction, meaning that the presence of active engagement buffered the relationship from the negative effects of protective buffering. This is important as research has shown that the style of support engaged in by the partner can fluctuate (Schokker et al, 2010).

Protective buffering can be seen as the opposite to active engagement, it involves hiding concerns, not sharing information, discouraging illness related discussion and avoiding arguments. A significant other may engage in this type of behaviour due to uncertainty of how to act, wanting to shield and unburden the patient, and beliefs around what may impact a patient's recovery (Hagedoorn et al, 2000). One study found that partners who engaged in protective buffering negatively impacted their partner's recovery from breast cancer (Lichtman, Taylor & Wood, 1988). In another study protective buffering predicted higher distress and lower self-efficacy in women with diabetes and overprotection (see definition below) predicted lower self-efficacy in both genders (Johnson et al, 2013).

Overprotection may stem from an underestimation of the patient's abilities and overestimation of the level of assistance required, leading to unhelpful support, excessive reinforcement for accomplishments and unnecessary restrictions. Significant others who engage in overprotection may do so due to a belief that their partner isn't coping or their own

inability to cope with caregiver burden (Hagedoorn et al, 2000). This type of support can make it difficult for the patient to develop self-efficacy and feel in control of their lives as well as leading to dissatisfaction in the relationship (Coyne & Smith, 1994; Hagedoorn et al., 2000). In one study when patient with type two diabetes received low AE and high OP support, dietary adherence critical to treatment was poor (Johnson et al, 2015). Another study found higher levels of overprotection predicted poorer adjustment to age-related vision loss (Cimarolli, Reinhardt & Horowitz, 2006).

Research has consistently shown that chronic illness can place a burden on the spousal relationship, and that conditions in which there is greater chronic pain or degeneration in physical or cognitive capacity place a greater burden than acute conditions (Badr, 2004). IBD in its severe form can be highly disabling and painful for the sufferer and is the definition of a chronic condition with its lifelong prognosis (Gaerry, 2006; Trachter, Rogers & Leiblum, 2002). Therefore, in relationships where the ill partner receives support in a mainly active engagement manner from their significant others, we would expect less negative impact on the relationship, greater relationship satisfaction and more self-efficacy in the patient. This in turn impacts upon health outcomes as self-efficacy and relationship satisfaction is related to positive illness outcomes (Uchino, 2006).

Most of the studies discussed in this section talk about received social support; however this is often measured through self-report questionnaires raising the question whether they are truly assessing received support or are in fact measuring perceived social support. As discussed above it may be perceived social support which is more relevant for the relationship between social support and physical illness (Uchino, 2009). One study compared male patient's perceptions of the support they received and their female partner's perceptions of the support they gave in terms of the impact on the patient's cardiac illness (Vilchinsky, Dekel, Leibowitz, Reges, Khaskia & Mosseri, 2011). They found that the effect of the

partners support was moderated by how the patient perceived that support, partners active engagement only had positive effect on health behaviours when the partners perceived that support as active engagement. Likewise overprotection only had a negative effect when it was perceived by the patients. Interestingly protective buffering only had a negative effect when it wasn't perceived by the patient. Another study looked at discrepancies between perceptions of protective buffering and overprotection in 68 patients with chronic obstructive pulmonary disease and their partners (Snippe, Maters, Wempe, Hagedoorn & Sanderman, 2012). They found distress was related to patient's perceptions of protective buffering and overprotection, again suggesting that in social support perception is important. No studies could be found that looked at the type of support provided and IBD. But given the findings discussed above it would be warranted to assess whether the type of support has an impact on the relationship between social support and IBD illness outcomes.

Social support and mental health. There is support in the literature for a relationship between social support and mood (Berkman, Glass, Brissette & Seeman, 2000; Kawachi & Berkman, 2001; Stice, Ragan & Randall, 2004; Grav, Hellzen, Romild & Stordal, 2012). When a person is diagnosed with clinical depression one of the recommended treatments is to increase their social contact and engage with others as opposed to withdrawing (Beck & Beck, 2011). The relationship between social support and mental health has been well established in the literature (see Lin, Dean & Ensel, 2013 for a review). For example one study found levels of perceived social support was significantly related to depression in 40,659 participants in Norway, even after controlling for potentially confounding factors (Grav et al, 2012).

Berkman and others present the theoretical models for the association between social support and mental health which include social integration and attachment theories. They suggest that social networks have an influence on mental health in a cascading process

starting from the psychobiological processes and going right to the wider macro-social processes. Specifically they present that social networks have an impact on mental health through four primary pathways; 1) the provision on social support, 2) social influence, 3) social engagement and attachment and 4) the provision of resources and material goods.

Kawachi and Berkman (2001) discuss the links between social support and mental health in terms of the buffering theory and the main effect theory. In regards to the in main effect theory they propose that the presence of social networks provide social influence, which promotes positive health related behaviours and positive affective states; this in turn has an effect upon neuroendocrine response to stress and mental health. Compared to this is the proposed pathway of the stress buffering model, in which the impact of a stressful event is moderated by the perceived availability of social resources. This occurs because the individuals appraisal of their ability to cope with a stressor is impacted upon by their assessment of the availability of support, this impacts whether they perceive the situation as stressful or not, if the situation is interpreted as a stressor this results in a negative cognitive and emotional response which leads to a physiological or behavioural response, which in turn negatively impacts mental health. As noted previously in this section the authors suggest that the main effect and buffering models are not mutually exclusive and represent different processes of social support (e.g. main effect structural and buffering functional) and therefore both of these models together explain the relationship between social support and mental health. Based on the findings discussed above social support appears to have an influence on psychological wellbeing, this relationship appears to work much in the same way as the relationship between social support and physical health.

Inflammatory Bowel Disease and Psychosocial Factors

Rates of IBD are on the increase in Western populations and present a significant health problem, half a century of research has shown an increase in the prevalence of UC and CD worldwide (Gearry et al, 2006). In 2013 approximately 15,000 New Zealanders were affected by IBD (Ministry of Health, 2013). The costs associated with IBD are also a significant consideration; Lion and colleagues (2012) interviewed forty-nine patients with CD in Canterbury (Lion, Gearry, Day & Eglinton, 2012). They examined the costs associated with CD in this specific population, which was then extrapolated to predict the costs across New Zealand, suggesting that CD alone is estimated to cost New Zealand \$62.6 million a year.

The costs of IBD can also be counted in other ways; CD and UC have both been found to significantly impact patients' quality of life and psychosocial functioning (Turnbull & Vallis, 1995; Matini & Ogden, 2015). It has been well documented that suffering from a chronic illness places many strains on a person, in multiple areas of life. Patients with some illnesses, such as diabetes and IBD, additionally have to find a way to cope with the associated social stigma. This can be particularly difficult for those suffering from IBD as their symptoms, such as diarrhoea and rectal bleeding, are generally considered by society to be 'taboo' subjects. The potential outcome of this is people being too embarrassed to ask for help and feeling unable to discuss their difficulties with others and elicit support (Casati, Toner, Roody, Drossman & Maunder, 2000). A review by Casati and colleagues (2000) searched the IBD literature to identify the main concerns of patients. They conclude that these are low energy, loss of control, body image concerns, social isolation, fear about the future and health risks, not wishing to be a burden, not reaching full potential, feeling dirty and lack of information about their disease. A further study supported this finding, de Rooy and colleagues measured the concerns of 259 patients with IBD (de Rooy et al, 2001). They found patients were equally concerned about psychosocial factors (e.g., life goals) as they

were about physical factors (e.g., energy levels). Through factor analysis they found that participants reported three main areas of concern; body image and interpersonal issues, physical wellbeing and disease related stigma (de Rooy et al, 2001). This research highlights that although patients with IBD share many of the ‘traditional’ concerns of patients with other chronic illness; they also have concerns which are unique to IBD due to the nature of their symptomology. Another factor which may impact IBD patients embarrassment is the lack of awareness in the general public of these diseases, despite them being fairly common. This may lead to situations where patients have to explain what they are suffering and their symptoms to those in their social network and experience negative reactions in result. The combination of lack of disease knowledge in the general population and patient embarrassment in explaining the disease may lead to social isolation and a lack of social support. In addition it may lead to negative experiences which may decrease the chances of asking for help in the future.

A qualitative study by Matini and Ogden (2015) investigated patient’s adaption to life with IBD is not a simple process. They interviewed 10 people with CD and 12 with UC, recruited from online support groups. They highlighted the impact the symptoms of IBD have on patients and drew attention to the fact that even when patients are considered to be in remission they may remain significantly impacted by fatigue. Secondary to having to cope with the physical symptoms of IBD, patients often have psychological or social consequences such as humiliation and shame and trying to continue to function socially or occupationally. IBD can present a significant challenge to manage in the workplace with fatigue, the need for toilet access and increased usage of toileting facilities. This may lead to embarrassing questions from co-workers, which if the patients feels to embarrassed to answer may lead to frustration and a lack of understanding.

A study by Taft and others (2012) looked at stigmatization of 191 participants with IBD on measures of health related quality of life, distress, self-esteem and self-efficacy, they found 36% reported internalized stigma. In addition the common treatments for IBD often have negative side effects for example; steroidal treatment can cause bloating and weight gain or treatment can involve embarrassing consequences, such as the need for a colostomy bag. Added to this is the finding that those with IBD are at an increased risk of developing colorectal cancer, with incidence rates reported between 0.2 to 5% in hospital and population samples (Tsianos, 2000), which may place additional worry and stress on patients.

It is clear that the quality of life in those with IBD is significantly impacted, Matini and Ogden (2015) found that successful adaption to life with IBD requires substantial psychological strength and cognitive processes. They identified three common themes in those who adjusted well; making sense of the illness, coming to terms with the impact of IBD on functioning, and coping with the common emotional reactions (anxiety, helplessness, and frustration). Central to the participants adjustment to life with IBD was developing their “new normal” (pg. 8), this involved readjusting expectations and goals to be achievable and realistic in the context of their functional abilities, as well as building a sense of strength and resilience. Another important aspect reported by participants in the study was developing socially supportive relationships in which they were able to share experiences; they noted support groups as being particularly helpful. In the development of this ‘new normal’. The authors highlight the importance of finding a balance between “one’s identity as a patient with IBD... (and) encouraging one’s sense of self and identity as a person who manages their chronic illness...rather than a patient whose existence revolves around this illness” (pg. 8; Matini & Ogden, 2015). IBD represents a unique challenge, like with most chronic diseases, as symptoms come to run one’s life and impact how they function as an individual. Finding

ways in which patients can be supported to adjust to life with IBD is important and may not affect just their quality of life but their mental health and physical wellbeing as well.

The impact of stress on IBD. The biological pathways between the stress response in the brain and outcomes in the gastrointestinal tract have been examined in various reviews and are known as brain-gut interactions (Bhatia & Tandon, 2005; Bonaz & Bernstein, 2013). One review states “psycho-neuro-endocrine-immune modulation through the brain-gut axis likely has a key role in the pathogenesis of inflammatory bowel disease” (Bonaz & Bernstein, 2013, pp.36). Various gastrointestinal diseases have been associated with chronic stress including functional bowel disorders, peptic ulcer disease, gastroesophageal reflux disease and IBD. This suggests that stress may have a role in the onset and course of IBD.

One study looked at the efficacy of reducing CD symptoms with a stress management intervention (Garcia-Vega & Fernandez-Rodriguez, 2004). Participants in the stress management condition reported significant reductions in tiredness, constipation, abdominal pain and abdomen bloating; compared to no significant changes in the treatment as usual group. A literature review by Maunder (2005) looked at the evidence for the influence of psychological stress, defined as when environmental demands exceed the adaptive capacity of the individual, on IBD. It was concluded that there are conflicting findings in the literature to date, but there is support for a relationship between stress in UC and depression in CD. A later review, which included nine longitudinal studies, supported this finding (Maunder & Levenstein, 2008). Other studies found both CD and UC were affected by stress, Duffy and colleagues (2010) conducted a 6 month prospective study of 124 UC and CD patients. Multiple regression analyses found the experience of a stressful life event to be the most significant indicator of disease activity but only accounted for 7% of the variation. Stress was more significant predictor than health perception, clinical severity (extent of bowel involvement, baseline activity), health behaviours (smoking) and socio-demographic features.

Based on these findings it seems reasonable to expect a relationship between life stress and disease severity on IBD, this relationship may be more evident in UC than CD but this remains unclear.

The impact of mental health on IBD. Recently the literature on the psychosocial influences of IBD has explored the association between depressive symptoms and disease activity. Mittermaier and colleagues (2004) looked at 60 participants with CD in an 18-month prospective study. Regression analysis identified a significant correlation between scores on the Beck Depression Inventory (BDI - II) at baseline and the total number of disease relapses after 18 months ($p < .01$). The participants BDI scores at baseline were found to significantly correlate with the time until the participant experienced their first relapse. This suggests that mood may have a significant negative impact on disease severity. A two-year prospective study with 18 participants found similar results (Mardini, Kip & Wilson, 2004). BDI scores were independently associated with CD activity at baseline ($p = 0.004$) and eight to twelve weeks later ($p = 0.004$). Disease activity was also associated with higher scores of anxiety, hopelessness and a recent life change, but not independently of depression. In their review Graff, Walker and Bernstein (2009) concluded that there is evidence that the course of IBD is worse in those patients with depressive symptoms. They presented several studies in which the fluctuations in disease activity were temporally related to the presence of depressive symptoms, although the causal direction in these studies is not clear. There appears to be a notable relationship between emotional state (as evidenced by depressive symptoms) and disease activity in IBD. With psychological wellbeing having an impact upon physical wellbeing (or physical wellbeing upon psychological wellbeing since the direction is not clear).

There is support in the literature for a relationship between social support and mental health including and impact of social support on mood (Stice, Ragan & Randall, 2004; Grav,

Hellzen, Romild & Stordal, 2012). Reducting social isolation and increasing positive social contact is one of the components of Cognitive Behavioural Therapy for Major Depressive Disorder (Beck & Beck, 2011). Given the relationship between social support and mental health, social support may be an important moderator in the relationship between mood and IBD disease course. Improving the social support perceived by a sufferer of IBD may therefore reduce their depressive symptoms and this in turn may have an impact on their disease severity. To my knowledge this is the first time this relationship has been explored with an IBD sample.

The Current Study: Exploring the relationship between social support and IBD.

As has been discussed above and proposed through various theoretical models social support is thought to have a notable impact chronic illness like IBD, however this aspect has received little attention in the literature. A limited amount of research has looked at the efficacy of various psychosocial interventions. Studies looking at the efficacy of relaxation and stress management interventions for IBD have been mixed; one review paper looked at five studies and found only one with a methodologically valid treatment effect (Keller et al, 2004, Maunder & Levenstein, 2008).

Another way to intervene with people who suffer from IBD could be to influence the relationship between psychological factors, such as stress and mood, and IBD. The preliminary research to date suggests that social support may be an area which intervention could be targeted to reduce the impact of psychological factors on disease course (Camara et al, 2011). Sewitch and colleagues (2001) looked at social support and disease activity in a cross-sectional study of 200 patients with IBD. They found that the relationship between psychological distress and perceived stress was moderated by level of satisfaction with social support ($p < .05$) and that psychological distress was related to disease activity ($p < .05$).

They also found satisfaction with social support was only related with psychological distress when there were high levels of perceived stress. They suggest there is evidence to treat IBD within a biopsychosocial framework and that improving social support may have a positive affect on psychological wellbeing and perceived stress, which ultimately would benefit individual's physical health as psychological wellbeing was related to disease activity..

Camara and others (2011) also supported this finding in their longitudinal study which looked at the effects of social support on disease activity in CD. Five hundred and ninety seven patients with CD were assessed over an 18-month period. They found the odds of a worsening of the disease course decreased by 1.5 times with a 1 SD increase of social support. They concluded that high levels of social support may have an effect on the clinical course of CD and that this was an area which has received little attentions and warrants further investigation.

Despite the empirical support for the idea that social support may moderate the disease course of IBD, acting as a buffer against the negative effects of stress and mental health, little research has been conducted in this area. Research has looked at the effects of social support on other diseases, such as cancer, and found an effect on disease course and prognosis (Ell, Nishimoto, Mediansky, Mantell & Hamovitch, 1992). Inflammatory bowel disease may be especially sensitive to the effects of stress due to the possible causal mechanism that have been implicated through the brain-gut interaction hypothesis. Additionally patients with IBD may be particularly vulnerable to psychological distress as IBD cab be socially isolating due to its symptomology and associated stigma. Interesting the impact of the type of social support has not been looked at with IBD patients as it has with other chronic illness such as cancer. The type of support received and perceived by patients may a have significant relationship on the course of their disease as this has been found with other chronic illnesses.

The aim of the current study was to investigate the role of stress, mental health and social support in IBD. I expect positively perceived social support provided in an active engagement manner to be related to better health outcomes and to protect the patients against the negative effects of stress and depressive symptoms. In addition I expect the type of social support provided to have a relationship with illness outcomes, with more positive outcomes for active engagement over protective buffering or overprotection. From the above discussion of relevant literature I made the following predictions;

1. When perceived social support is high, and provided in an active engagement manner illness severity will be low.
2. When stress is high, illness severity will be high.
3. When depressive symptoms are high, illness severity will be high.
4. Social support will moderate the relationship between stress and severity. This will be shown by a stronger relationship between stress and illness severity with low levels of social support and a weaker relationship with higher levels of social support.
5. Social support will moderate the relationship between depressive symptoms and severity. This will be shown by a stronger relationship between depressive symptoms and illness severity with low levels of social support and a weaker relationship with higher levels of social support.

Method

Participants

This study was approved by the University of Canterbury Human Ethics Committee (HEC 2015/22; see Appendix A). Participants were 60 individuals with a medical diagnosis of inflammatory bowel disease. Participant demographics are summarized in Table 1. The sample was predominately women of European descent with CD. The majority of participants ($n = 41$) received support from a spouse or partner and received their diagnosis 2 or more years ago.

Table 1
Sample Demographics

	<i>n</i>	<i>M</i>	<i>%</i>	<i>SD</i>
Age		34		11.8
Gender				
Male	9		15.0	
Female	51		85.0	
Ethnicity				
NZ European	53		88.3	
Other	7		11.6	
Diagnosis				
Crohn's disease	46		76.7	
Ulcerative Colitis	14		23.3	
Time since diagnosis				
1 – 6 m	7		11.7	
6m – 1y	1		1.7	
1 – 2y	2		3.3	
2 – 5y	17		28.3	
5 – 10y	18		30.0	
10y +	15		25.0	
Support person				
Spouse/Partner	41		68.3	
Mother	12		20.0	
Father	2		3.3	
Sister	1		1.7	
Friend	2		3.3	
Other	2		3.3	

Participants responded to an advert about the study which was posted to social media and IBD social support groups (see Appendix B). Participants gave their informed consent online by selecting ‘yes’ after reading through the information (Appendix C) and consent form (Appendix D). Those who completed the questionnaire were entered into the draw to win an iPad Mini or a \$150 Westfield voucher.

Procedure and Design

Participants diagnosed with IBD (CD or UC) were recruited from the general population of New Zealand and offered the chance to win a voucher for their participation. Recruitment was conducted through flyers, print and online media targeting support groups for IBD. Participants who agreed to participate followed a link to an online questionnaire (see Appendix E), the first page of which was the consent form (Appendix D) detailing what their participation would involve. If they were happy to continue they did so by selecting the ‘yes’ option which allowed them access to the questionnaire. The questionnaire was administered by the participant reading each question and selecting an option. Once they reached the end the participant was thanked for their time and given a chance to request the outcome of the study as well as to enter the prize draw. In addition they received information about where they could get assistance if their participation caused them any distress (see Appendix F).

Measures

Participants completed a questionnaire online using Qualtrics Survey Software. The questionnaire contained eight self-report measures and a brief section of seven demographic questions. The measures assessed disease severity, presence and type of social support, mental health, stress and quality of life.

Disease severity. Participants completed different severity measures depending on their diagnosis. The Simple Clinical Colitis Activity Index was developed as a brief screening tool to aid medical practitioner's assessment of their patient's current disease severity but in the current study it was used as a self-report measure (Walmsley, Ayres, Pounder & Allan, 1998). The index was based on an established measure, The Powell-Tuck Activity Score, but included additional clinical information identified in research since the Powell-Tuck measure was created. The index assesses the frequency, urgency and presence of blood in bowel movements, extracolonic features and general wellbeing, an example item is "*on average how many times a day did you move your bowel over the last month*". When compared to established and more complex measures of disease severity the index was found to be valid (Powell-Tuck Index $r = 0.959$, $p < 0.01$; Complex Index $r = 0.924$, $p < 0.01$) as well as medical tests (laboratory markers $p < 0.5$).

The Harvey-Bradshaw Index (HBI; Harvey & Bradshaw, 1980) is a simpler version of the Crohn's Disease Activity Index (CDAI), and it does not require biochemical testing. The HBI is designed to measure the severity of disease activity in CD. Although the HBI is consistently cited to be a valid and reliable measure no validity studies could be found, however studies have found the HBI to have convergent validity with other measures such as the CDAI (Harvey & Bradshaw, 1980). Items included "*How is your general well-being*" and "*do you experience any complications currently*". A score of 3 or less is considered to be in remission and a score of 8 or more is considered to be diseased.

Mental health, distress and stress. The Patient Health Questionnaire (PHQ-9; Kroenke & Spitzer, 2002) is a nine-item self-report inventory designed to measure depression and has been found to have convergent validity with the Beck Depression Inventory, but is freely available (Kroenke, Spitzer & Williams, 2001). Responses are given

on a 4-point Likert scale (0 = not at all, 3 = nearly every day) an example item is “*Over the last two weeks have you been...feeling down, depressed, hopeless*”.

The short-form version of the Depression anxiety stress scale (DASS-21; Lovibond & Lovibond, 1995) is a 21 item measure of mood (e.g., “*I couldn’t seem to experience any positive feeling at all*”), anxiety (e.g., “*I was aware of a dryness of my mouth*”) and stress (e.g., “*I found it hard to wind down*”). Participants are asked these questions in regards to the last week and respond on a 4- point Likert scale (0 = never, 4 = almost always).

Cohen’s Perceived Stress Scale (PSS; Cohen & Williamson, 1988) is a reliable and valid measure of the degree to which participants perceive their lives as uncontrollable, unpredictable and overloading (e.g., “*In the past month how often have you felt unable to control the important things in your life*”). Responses are given on a 5-point Likert scale (0 = never, 4 = very often).

Social support. A short eight item questionnaire was used to assess support received from the most important significant other in the person’s network during the past month. Participants were asked who their most important support person was and answered the questions in relation to this person. The measure (7 items) assessed practical support (e.g., “*did this person give you information or advice*”) and emotional support (e.g., “*were you able to trust, talk to frankly, and share your feelings with this person*”) on a 7- point Likert scale (1 = not at all, 7 = very much; see Appendix E for full questionnaire). These items were a combination of questions from the Significant Others Scale developed by Power, Champion and Aris (1988) and questions based on work from Bridges, Sanderman and Van Sonderen (2002). A further item was included and assessed their satisfaction with the social support received from this person.

The Active Engagement, Protective Buffering and Overprotective (ABO)

questionnaire was developed to assess the different ways in which partners can provide support to those suffering a chronic illness (Buunk, Berkhuysen, Sanderman, Nieuwland & Ranchor, 1996). It was based on the work of Coyne and others on active engagement (e.g., “*my support person tries to discuss it with me openly*”), protective buffering (e.g., “*my support person tries to hide his or her worries about me*”) and overprotection (e.g., “*my support person treats me like a baby*”) (Coyne, Ellard & Smith, 1990). For this study the word “partner” was changed to “support person”, participants were asked whether their support person acted in the above ways when supporting them on a 5-point Likert scale (1 = never, 5 = very often).

The Multidimensional scale of perceived social support (MSPSS; Zimet, Dahlem, Zimet & Farley, 1988) is a reliable and valid 12-item measure of a person’s perception of the social support they receive. It is broken down into three subscales; significant other, friends and family with four items in each subscale. It assesses perceived support from family (e.g., “*my family really tries to help me*”), friends (e.g., “*I can count on my friends when things go wrong*”) and significant others (e.g., “*there is a special person in my life who cares about my feelings*”) on a 7-point Likert scale (1 = very strongly disagree, 7 = very strongly agree).

Quality of life. Quality of life was assessed using a single question based on Cantril’s Ladder. Participants were asked to rate their quality of life on a scale from 0 (worst possible) to 10 (best possible).

Statistical Analyses

SPSS version 22 (Statistical Product and Service Solutions) was used for the descriptive and inferential analyses. To investigate the study hypotheses correlational, between groups and hierarchal multiple regression analyses were conducted.

First, preliminary analysis involved testing the reliability of the measures by calculating the alpha coefficients as shown in Table 1. There was no information missing from the data set with all 60 participants having completed the questionnaire correctly. Two participants completed the severity measures for both illnesses; the data for the unnecessary measure was deleted based on their diagnosis. Due to the low number of participants with UC the severity ratings were combined to achieve the greatest power. This was done by transforming the data from the separate measures into Z scores to create a single measure of severity. The PHQ, DASS and PSS measures needed to be recoded due to a difference between the Qualtrics (e.g. 1-4) and the proper rating scale (e.g. 0-3); this was done by recoding the data into the same variables. Three items needed to be reverse coded, then item total scores were created. No outliers existed, therefore no participants were removed. Hierarchical linear regression was used to test for the moderation analyses with severity being the dependent variable. To avoid high multicollinearity, the variables were centred and interaction terms were created (MSS x PSS, MSS x PHQ and MSS x DASS D). The independent variable (MSS and PSS, MASS and PHQ, MSS and DASS D) were entered in the first step of the regression, the interaction term was entered in the second step.

Results

Table 2 presents the descriptive statistics for all the measures included in the questionnaire. The protective buffering scale had a very low Chronbach's alpha in the current sample but was included in the analyses; however the results with this scale should be interpreted with caution due to its low reliability. All the other measures showed acceptable internal consistency (all above .7).

Table 2

Means, Standard Deviations and Reliability coefficients of all measures

Measures	M	SD	Cronbach's alpha
<u>Mental Health</u>			
<i>PHQ</i>	8.7	5.6	.873
<i>DASS</i>			
Depression	4.2	4.1	.925
Anxiety	7.4	4.1	.808
<u>Stress</u>			
<i>PSS</i>	19.1	8.6	.920
DASS Stress	6.8	4.4	.893
<u>Social Support</u>			
<i>SP</i>	40.4	8.2	.748
<i>ABO</i>			
Active engagement	18.7	4.0	.881
Protective buffering	21.5	4.3	.456
Overprotection	13.6	4.6	.723
<i>MSS</i>			
Family	21.8	5.6	.925
Friends	21.3	5.0	.932
Significant other	23.4	5.4	.895
Total	66.5	13.0	.920
<u>Quality of life</u>			
<i>QOL</i>	7.2	2.0	
<u>Illness severity</u>			
<i>Crohn's disease</i>	8.0	3.2	
<i>Ulcerative Colitis</i>	8.2	1.8	

On both measures of disease severity participants scored on average in the diseased range (which was 8 and above). In regards to mental health, moderate rates of symptoms

were reported by the sample on the PHQ-7 with the average falling in the mild range for depression (5 - 9) however the average on the DASS depression fell in the normal range (0-4). The average for the DASS anxiety fell in the moderate range (6-7). The sample reported high levels of stress, with the average score on the PSS falling in the moderately stressed range (14-26) but in contrast to this and the DASS stress averaged in the normal range (0 – 7). On average quality of life was rated fairly positively (7.2 out of 10). Participants on average rated their levels of social support positively, the highest average on the ABO questionnaire was for the active engagement style and the lowest was for the overprotective style. On the MSS the total average rating was 66.5 out of a possible 84 with the highest average for support from a significant other, and on the SP the average was 40.4 out of a possible 56. This indicated substantial levels of perceived social support with higher scores on the measures of perceived social support.

It was important to assess whether there was any significant difference between disorder types in terms of their responses to the measures. As shown in Table 3 there were no significant between group differences.

Table 3

Differences between groups on measures of stress, mental health, quality of life and social support.

	Crohns Disease	Ulcerative Colitis		
<u>Variable</u>	<u>M (SD)</u>	<u>M (SD)</u>	<u>t</u>	<u>p</u>
Social Support (MSS)	67.8 (12.7)	61.9 (13.3)	1.56	.125
Social Support (SP)	40.8 (8.3)	40.3 (8.4)	0.08	.940
Social Support ABO				
AE	18.7 (4.2)	18.4 (3.7)	0.20	.844
PB	22.0 (4.5)	20.0 (3.1)	1.63	.108
OP	13.6 (4.6)	13.4 (4.7)	0.14	.886
Stress (PSS)	20.1 (8.8)	15.7 (7.0)	1.70	.095
Stress (DASS)	7.0 (4.9)	6.3 (2.6)	0.51	.613
Anxiety (DASS)	7.6 (4.4)	6.5 (3.0)	0.75	.348
Depression (DASS)	4.1 (4.3)	4.6 (3.5)	-0.37	.713
Depression (PHQ)	8.8 (5.7)	8.4 (5.7)	0.20	.839
QOL	7.2 (2.0)	7.3 (1.5)	-0.12	.908

Correlational Analyses

Social support and severity. As presented in Table 4 correlational analyses show that there were significant negative relationships between social support as assessed by the MSS and severity, except for MSS family ($p < .01$). This indicates that participants with lower perceived social support have higher illness severity. No significant correlations were found between other the other measures of social support and severity (SP and ABO). Therefore there were no significant correlations between the different types of support provided, active engagement and overprotection, and illness severity (ABO) and perceived social support and illness severity (SP).

Table 4

Self-report illness severity and social support measures: Bivariate zero-order correlations (N = 60)

	1	2	3	4	5	6	7	8
1. Severity	-							
2. SP	-.125	-						
3. ABO Active	-.129	.660**	-					
4. ABO Overprotection	.146	-.171	.076	-				
5. MSS Sig other	-.411**	.605**	.445**		-.076	-		
6. MSS Friends	-.415**	.604**	.502**		.119	.753**	-	
7. MSS Family	-.131	.128	.356**		-.050	.325**	.392**	-
8. MSS Total	-.398**	.558**	.535**		.000	.861**	.890**	.686

*p<.05. **p<.01.

Stress and severity. Correlational analyses were conducted to see whether there was a relationship between participant's levels of perceived life stress and their reported level of illness severity. As shown in Table 5 there was a significant positive relationship between stress, as measured by the DASS S and illness severity ($p < .05$) but not between stress as measured by the PSS measure and severity. This means that those with high severity also reported stress symptoms as indicated by the DASS S, while PSS was not significant ($p = .093$).

Table 5

Self-report illness severity and life stress: Bivariate zero-order correlations (N = 60)

	1	2	3
1. Severity	-		
2. PSS	.219	-	
3. DASS S	.292*	.709**	-

*p<.05. **p<.01.

Mental health and severity. As above, correlation analyses were used to examine the relationship between mental health and illness severity. As shown in Table 6 there were significant positive relationships ($p < .05$) between all measures of mental health, and illness severity; indicating that participants who reported high levels of mental health symptoms also reported their illness symptoms as more severe. Additionally, there was a significant negative relationship between quality of life and illness severity, suggesting that a low quality of life is related to high illness severity.

Table 6

Self-report illness severity and mental health measures: Bivariate zero-order correlations (N = 60)

	1	2	3	4	5
1. Severity	-				
2. PHQ	.287*	-			
3. DASS D	.330*	.813**	-		
4. DASS A	.289*	.715**	.736**	-	
5. QOL	-.302*	-.156	-.131	-.095	-

* $p < .05$. ** $p < .01$.

Moderator Analyses

Social support as a moderator of stress and illness severity. Social support was examined as a moderator of the relationship between stress and illness severity. The MSS was used due to it being a measure of perceived social support and the only measure to have a significant correlational relationship with illness severity. The PSS measure was used due to its well established validity as a measure of perceived stress. As shown in Table 7 Social support (MSS) and stress (PSS) accounted for a significant proportion of the variance in severity $R^2 = .209$, $F(2,57) = 7.55$, $p = .001$. The interaction term did not explain a significant change in illness severity $\Delta R^2 = .01$, $\Delta F(1,56) = .956$, $p = .332$.

Social support as a moderator of depression and illness severity. Again hierarchical multiple regression was used to test the hypothesis that social support moderates

the relationship between depression and illness severity. Both the DASS depression scale and the PHQ was used in this analysis due to both of these measures having significant correlational relationships with illness severity. As shown in Table 7 Social support (MSS) and depression (DASS D) accounted for a significant proportion of the variance in severity $R^2 = .20$, $F(2,57) = 7.06$, $p < .05$. The interaction term did not explain a significant change in illness severity $\Delta R^2 = .01$, $\Delta F(1,56) = .621$, $p = .434$.

The same result was found when looking at the PHQ; Social support (MSS) and depression (PHQ) accounted for a significant proportion of the variance in severity $R^2 = .201$, $F(2,57) = 7.17$, $p < .01$, again the interaction term did not explain a significant change in illness severity $\Delta R^2 = .000$, $\Delta F(1,56) = .022$, $p = .882$.

Table 7
Moderating effect of social support on relationship between illness severity and stress and illness severity and depressive symptoms

		$R^2\Delta$	β	B
<u>Stress</u>				
Step 1	PSS	.209*	.201	.027
	MSS SO		-.397	-.073
Step 2	PSS x MSS	.013	-.118	-.003
<u>Depressive Symptoms</u>				
Step 1	DASS depression	.199*	.190	.041
	MSS SO		-.331	-.061
Step 2	DASS d x MSS	.009	-.102	-.004
Step 1	PHQ	.201**	.186	.033
	MSS SO		-.359	-.066
Step 2	PHQ x MSS	.000	-.112	-.001

* $p < .05$, ** $p < .001$

In summary neither of the moderation hypotheses was supported through data analysis with the adding of the interaction term not resulting in significant change in variance

as indicated by change in R^2 . This means that the level of social support did not have a significant impact on the relationship between stress and illness severity and depressive symptoms and illness severity in this sample. Further exploration of the data revealed no significant moderation interaction with any of the other social support variables (ABO and SP).

Discussion

Summary of Findings

Social support has been found to have an impact on disease outcomes in patients with chronic illnesses (Uchino, 2006) including IBD (Camara et al, 2011). The aim of the current study was to examine the relationship between illness severity and possible influencing factors such as social support, life stress and mental health. Additionally I investigated the moderating effect of social support on the relationship between stress and illness severity, and depression symptoms and illness severity. Five hypotheses were derived: a predicted relationship between illness severity and 1) perceived social support and support type, 2) stress, 3) depressive symptoms, furthermore social support will moderate the relationship between 4) stress and severity and 5) depressive symptoms and severity.

Overall it was found that illness severity did have a relationship with social support and depressive symptoms, and one measure of stress but not with type of social support, as well as anxiety symptoms and quality of life. Statistical analysis did not support any moderator relationships between social support and severity meaning I was unable to support previous finding which found that for patients with IBD, social support acts as a buffer against the negative affect of stress and low mood on illness severity (Sewitch et al, 2001; Camara et al, 2011).

Correlational Relationships

Social support and severity. Based on previous research and theory I predicted that participants with high levels of perceived social support would have lower levels of illness severity (Sewitch et al, 2001; Keller et al, 2004; Maunder & Levenstein, 2008; Camara et al, 2011). The results supported this hypothesis as there was a significant negative correlation

between perceived social support as measured by the MSS total and illness severity. There were differences in the relationship between illness severity and the subscales of the MSS. MSS significant other and MSS friends was significantly negatively related to severity, meaning that participants with low levels of social support from significant other or friends, had higher rates of disease severity. This was not found with MSS family however, this may be because participants had closer relationships with their partner and friends than their family; however this was not measured so it is not clear why I found this difference.

No significant relationships were found between illness severity and the other measures of social support (SP and ABO). The SP measured received social support, the suggested differences between perceived and received support in terms of their impact on disease severity may explain why I did not find a significant relationship. With research suggesting a more consistent relationship between perceived social support and illness outcomes (Uchino, 2009). There were no significant relationships between the type of social support and illness severity, this is the first time this aspect of social support has been looked at with this type of sample (IBD) and this outcome variable (illness severity). Therefore it is possible that although the type of social support has been found to have an impact on relationship satisfaction and psychological distress in previous research, it may not have an impact on the physical aspects of chronic illnesses. To my knowledge this is the first time that the impact of the type of social support has been investigated with an IBD sample therefore it is hard to draw conclusions. It is important to note, as with all correlational research, the direction of causality is not clear. Participants with lower illness severity may be able to pay more attention to their social networks and are therefore more perceptive of the support they receive.

Stress and illness severity. Due to consistent findings on the relationship between social support and stress we predicted that participants with high levels of stress would have

high levels of illness severity. This was partially supported with one measure showing a significant relationship (DASS S) and one not (PSS). One aspect which may account for the difference in findings between the two measures of stress is the variance in what they assess. The DASS stress is a measure of physical stress symptoms, such as the inability to relax, whereas the PSS measured the extent to which participants perceived their lives as controllable and is therefore a subjective measure of perceived stress. We may have found a relationship between DASS stress and illness severity and not the PSS because it may be that the physical symptoms of stress impact upon illness severity due to them having a physical effect on the body. Whereas the perception of a stressful life may not impact upon illness severity as it can be influenced by personality factors and cognitive processing, and therefore may not be related to the actual amount of stress the person is exposed to.

In addition the DASS was created to discriminate between depression, anxiety and stress but takes into account the shared causes of these aspects and therefore also measures stress as a psychological aspect (Osman et al, 2012). Whereas the PSS again is a measure of perceived stress, that is the patient's cognitive appraisal of stressors, and are therefore susceptible to social influences. This may explain why we found a difference between the two measures as we found significant correlations with all mental health measures and disease severity indicating that psychological aspects in this sample were correlated with illness severity.

However there was significant variation between the measures in terms of the average severity level, with the mean of the PSS being in the moderate stress range and the mean of the DASS stress being in the normal range. This makes the findings harder to interpret as it is surprising that I found a relationship between illness severity and the measure on which participants placed themselves in the normal range, and not the measure on which they reported experiencing moderate amounts of stress. It may be that due to experiencing

intense physical symptoms from IBD, the physical symptoms of stress go unnoticed by participants despite them potentially having an impact on the severity of IBD symptoms. Additionally this finding could also be a result of successful adaption by participants in this sample. Matini and Ogden (2015) note that sufferers of IBD can adapt to life with IBD by creating a 'new normal' and modifying their environment to suit their new abilities. By going through this process patients may come to accept the degree of stress in their lives with IBD and the physical symptoms of stress less upsetting. High rates of social support were also reported by this sample which may have aided in this process of adapting as participants in this sample would have been able to lean on supports in times of stress, thereby potentially reducing the harmful impact of perceived stress on their illness severity.

Mental health and illness severity. Based on emerging literature on the relationship between depression and IBD (Mittermaier et al, 2004; Mardini, Kip & Wilson, 2004; Graff, Walker & Bernstein, 2009) it was predicted that participants with high levels of depressive symptoms would have high levels of disease severity. This relationship was found on all measures of depression as well as other measures of mental health (anxiety) and quality of life. It is important to note that the direction of causality is not clear, those with more severe IBD are likely to have a lower quality of life and a more restricted life which may have a significant impact upon their psychological wellbeing. It is therefore to be expected they would have higher levels of depressive symptoms (Graff, Walker & Bernstein, 2009) and may develop comorbid clinical disorders such as major depressive disorder or health related anxiety. Of note are the moderately high levels of mental health symptoms reported by the participants in this sample. The sample on average fell in the mild range for depression and moderate range for anxiety, despite this, participants rated their average quality of life positively.

My finding of a significant correlational relationship between illness severity and depressive symptoms is in keeping with the results of previous studies which suggest that depression has an impact on the course of IBD symptoms (Mittermaier et al, 2004; Mardini, Kip & Wilson, 2004; Graff, Walker & Bernstein, 2009). In addition previous studies have also found the same relationship between quality of life and disease course in IBD (Graff, Walker & Bernstein, 2009). However, again it is important to note that in my study the direction of causality is not clear, as we would expect those with higher disease severity to have a lower quality of life and poorer psychological wellbeing. However these findings have been found in studies with longitudinal designs (Mittermaier et al, 2004; Mardini, Kip & Wilson, 2004).

Moderator Analyses

Social support as a moderator of stress and illness severity. I predicted that positive social support would shield participants against the potentially negative impact of stress on their illness severity. This was based on previous research suggesting that social support acts as a buffer to protect patients against the potentially harmful effects of stress on disease course in IBD (Sewitch et al, 2001; Camara, 2011). This interaction was not supported by statistical analyses in the current sample. It is likely that our small sample size, and accompanying low statistical power contributed to our inability to find a moderation interaction. As this finding is in contrast to research done by Camara and colleagues (2011) which did support a moderating relationship of social support on CD illness severity in a large sample (n = 597) longitudinal study. In addition stress was inconsistently found to be related to disease severity in this sample with one measure having a significant relationship and one not, this may have impacted our ability to find a moderation interaction.

Furthermore the demographic makeup of the sample may also be a contributing factor as it was predominately women who participated. In their review on the health benefits of social relationship Umberson and Montez (2010) present research that suggests that men may benefit more from intimate relationships in terms of physical health, than women. In fact there is some evidence from large scale population studies that mortality in women is related to high social support in some age groups (Shumaker & Hill, 1991). However this finding focuses more on the direct that being in a relationship has on health related behaviours, such as diet and exercise, and not potential of social support to act as a buffer between stress and illness severity. In addition this sex difference has not been looked at in a IBD sample so whether this is an influencing factor is hard to determine.

Adjustment to IBD is another a potential influencing factor that I did not measure or control for, Matini and Ogden (2015) suggest that quality of life is impacted in those who do not adapt to life with IBD. Despite experiencing significant disease and mental health symptoms, participants in this sample rated their QOL positively. This may suggest participants have adapted to life with IBD and created their “new normal”, making the necessary changes to their lives to function successfully with IBD. Thereby potentially reducing the negative impact of stress on disease activity as they accept that their life will have a degree of uncontrollability and adapt to coping with this. This may impact findings in this area, it is important that future studies consider the impact of adjustment to chronic illness when researching social support.

Social support as a moderator of depressive symptoms and illness severity. Due to the studies showing a relationship between depression and disease severity, combined with the research on the relationship between depression and social support, social support was predicted to moderate the relationship between depression and illness severity. This was not supported by the results in this sample. This is despite participants reporting mild depressive

symptoms. Again this may have been the result of low statistical power, however the relationship between depression and illness severity has been more consistently reported with Crohn's disease sufferers. To see whether this had an impact on my findings I conducted the regression analysis with Crohn's disease patients only ($n = 46$) but still found no significant moderation relationship. This is the first time to my knowledge that social support has been looked at as a moderator on the relationship between depression and illness severity in IBD. It may be that the physical impact of depression on the course of IBD is too strong to be impacted upon by social support but any conclusions are premature at this point until this relationship is explored to future investigations.

My findings support other research which shows high levels of comorbidity between IBD and depression (Graff, Walker & Bernstein, 2009). Only four participants in our sample reported being diagnosed with clinical depression despite the average reporting mild levels of depressive symptoms. Recent evidence has suggested inflammation as a causal factor in some types of depression (Raison, Capuron & Miller, 2006; O'Donovan, 2014). This may explain why there are elevated levels of comorbidity between depression and IBD. It may also explain why social support does not moderate the relationship as it is unclear whether social support has an impact on depression that is caused by inflammation as opposed to negative cognitions and/or significant life events.

Implications

This study supports the notion that people with IBD benefit from perceiving that they have positive support networks around them. As previously reported IBD can be an extremely debilitating and isolating disease with significant social stigma which can make it difficult for patients to seek help (Casati et al, 2000; de Rooy et al, 2001). The current study support to the finding that the perception of positive relationships has an impact upon illness

severity (Sewitch et al, 2001; Camara et al, 2001). The majority of the participants in the current study received support from a significant other highlighting the importance of intimate partners. Sufferers of IBD and their partners may benefit from interventions to improve their relationships or information on how to increase access to support such as engaging with support groups both in person or online or even creating ones themselves if they are not available in their area.

This study tentatively supports the suggestion that perceived social support is more consistently related to physical health outcomes than received support as we found a relationship between perceived support and illness severity (Uchino, 2009). Our results failed to support the buffering hypothesis as social support was not found to significantly impact the relationship between stress or depressive symptoms and illness severity (Schawrzner & Leppin, 1991). Our results do support the main effect theory with social support being related to illness severity. Kawachi and Berkman (2001) suggest the theories are interrelated and account for different process of social support, suggesting our findings have reinforced the importance of the structural characteristics of social support on the disease course but not the functional aspects in this limited sample.

I was not able to find a relationship between support type and illness severity as predicted by the research on active engagement, protective buffering and overprotection (Coyne & Smith, 1994). This was interesting given the findings with other chronic illness on the impact of 'negative' social support (Coyne & Smith, 1994; Hagedoorn et al, 2000). However the literature in this area so far has only looked at mental health and relationship satisfaction as the outcome variable. This is the first time, to my knowledge; support type has been looked at with illness severity as the outcome measure so any explanations would be premature. It may be that for patients with IBD, due to the significant stigma and

embarrassment which can make it hard to elicit support, any support is valued by the patient and this may lessen the negative impact of overprotection.

Of particular importance is the high comorbidity of depressive symptoms and IBD found in this and other studies (Graff, Walker & Berstein, 2009). Regardless of whether this depression is caused by shared biological factors (inflammation) or through psychosocial factors (isolation, negative cognitions, reduced quality of life, and reduced physical activity) it presents a significant consideration for sufferers of IBD, their loved ones and medical providers. The strength of the evidence showing the high rate of comorbidity justifies assessment for depression being routinely included in IBD assessment. Medical professionals should be screening their patients for mental health difficulties and referring them to appropriate services when required. The need for this is supported by the current study as only four participants reported a clinical diagnosis of depression in our sample. Graff and others (2009) highlight an important aspect for the management of IBD patients with comorbid depression, noting that relapse may be a particularly vulnerable time for their mental wellbeing and patients should receive particular support during this time. In addition, the presence of depression may impact medication adherence and other disease related health behaviours such as keeping up with regular blood tests (a requirement of some medications for IBD) and more general health related behaviours such as diet and exercise which can impact disease outcomes. Consensus guidelines made in 2009 for the management of Crohn's disease recommend screening for anxiety and depression and the importance of accessing appropriate treatments (Van Assche et al, 2009).

Limitations and Future Research

A number of methodological limitations can be identified in the present study. As noted previously this study is limited by a small sample and limited power, future research in

this area should be conducted with larger samples. In addition I did not account for potentially confounding variables such as socio-economic status, age, race, gender, comorbid physical and mental health conditions, differences in life stress, adjustment to IBD and so forth. Research has suggested sex, gender, age and education differences in the size and diversity of social networks and differences engagement with social networks (Umberson & Montez, 2010). Couples with less financial resources may face more life stressors, and are more likely to divorce or experience significant relationship conflict (Clarke & Berrington, 1999; Umberson & Montez, 2010). These group differences were not accounted for in the current study.

Another limitation of our study was the way in which I measured illness severity. I did not have the capability to use the ‘gold standard’ of severity testing which would have been assessing inflammation levels through blood testing. Therefore I used self-report measures which are typically used as assessment tools for medical professionals but have been utilized in research. I used two separate measures for the different diseases but due to low sample size had to combine the measures. This may have impacted the validity of the scores. Future studies should avoid this issue by using a single measure of disease severity. There is some evidence to validate the use of the Harvey Bradshaw with UC patients (Sewitch et al, 2001). With data showing that scores on the HBI are moderately correlated with intestinal inflammation in both CD and UC patients (Mahmud, McDonald, Kelleher & Weir, 1996).

In the current study illness severity did have a correlational relationship with social support. This suggests that exploring the interaction between these factors continues to be a valid line of investigation. Little is known about the causes of IBD and factors which influence the course of the diseases. This study adds to the evidence that social support and quality of life may have an impact on the disease course of IBD, in addition participants

reported mild rates of mental health symptoms and high levels of life stress, these aspects should be important considerations in a biopsychosocial approach to wellbeing from multiple professionals. Future research should continue to tease out the complex interplay between these factors. Of interest would be any differences between illness types in terms of these factors. CD seems to have been more consistently linked to depression in the literature and UC to stress (Maunder, 2005; Maunder & Levenstein, 2008). In addition a more in-depth look into the types of social support in terms of active engagement, protective buffering and overprotection would be warranted with a larger sample, as well as examining participants' support networks to determine variations and impact of received support compared to perceived alone. Furthermore, future research would benefit by minimising any of the noted limitations where possible.

Conclusion

The present study aimed to assess whether the illness severity of patients with IBD was related to stress, social support and mental health. Additionally this study sought to find whether social support moderated the relationship between stress and illness severity, and depressive symptoms and illness severity in patients with IBD. Significant correlational relationships were found between social support, stress, mental health, quality of life and illness severity but no significant moderation relationships were found.

Due to the limited research in this area it remains unclear whether social support acts as a buffer for patients with IBD, reducing the harm of stressful life events and negative mental states. A number of methodological limitations may hinder the conclusions made from this study including limited power and measurement validity and limited inferences can be made from correlational research. However the current study lends support to a

biopsychosocial approach to care for patients with IBD, one in which their mental health needs as well as physical health needs are assessed and treated.

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Appendix A

HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen

Email: human-ethics@canterbury.ac.nz



Ref: HEC 2015/22

16 April 2015

Siobhan Hayde
Department of
Psychology
UNIVERSITY OF CANTERBURY

Dear Siobhan

The Human Ethics Committee advises that your research proposal “In sickness and in health: social support and inflammatory bowel disease” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 10 April 2015.

Best wishes for your project.

A handwritten signature in black ink, appearing to read 'Lynda Griffioen'.

Yours sincerely

Chair University of Canterbury Human Ethics Committee

Appendix B



Diagnosed with Crohn's or Colitis?

Research participants wanted

We are looking for participants aged 18 years and older with a diagnosis of either Crohn's disease or Ulcerative Colitis to complete two online questionnaires three months apart.

Each questionnaire will take approximately 20-30 minutes to complete and will ask questions about your mental and physical well-being and the social support you receive from others. Those who complete the 1st questionnaire will go into a draw to win a \$150 Westfield voucher. Participants who complete both questionnaires will go into a draw for an Apple iPad mini.

This research is being carried out by Siobhan Hayde, and supervised by Associate Professor Roeline Kuijer of the University of Canterbury, Department of Psychology.

If you are interested in participating or wish to know more please contact,

Siobhan Hayde: siobhan.hayde@pg.canterbury.ac.nz

This research has been approved by the University of Canterbury Human Ethics Committee

Appendix C

Information Sheet



Department of Psychology
Email: siobhan.hayde@pg.canterbury.ac.nz
05.11.2014

In Sickness and in Health: Social Support and Inflammatory Bowel Disease Information Sheet for participants

Thank you for your interest in the study.

My name is Siobhan Hayde, and I am a first year clinical psychology student at the University of Canterbury. I am conducting this research as part of my Masters in Psychology. This study aims to contribute to the understanding of how our psychological health can impact our physical health by exploring the relationship between social support and disease severity in participants with Inflammatory Bowel Diseases (IBD).

What does participation involve?

Participation in the study involves completing two online questionnaires, three months apart. Each questionnaire will take 20-30 minutes to complete. In the questionnaires you will be asked to answer questions about your mental and physical well-being (including questions about disease activity), stress levels, mood and experience of social support. Those who complete the 1st questionnaire will go into a draw to win a \$150 Westfield voucher. Participants who complete both questionnaires will go into a draw for an Apple iPad mini.

Who can participate?

Anyone over 18 years of age with a medically confirmed diagnosis of either Crohn's disease or Ulcerative Colitis.

Risks

It is not anticipated that participation in the study will involve any risk to you. However, if after completing the questionnaire you are concerned about your health or you experience distress and want to talk to someone, we suggest you contact your general practitioner or contact any of the following support providers listed at the bottom of this letter.

Right to withdraw

Participation is voluntary and you have the right to withdraw at any stage without penalty until one month after submitting your questionnaire. If you withdraw, I will remove any information relating to you.

Confidentiality

The results of the project may be published, but you may be assured of the complete confidentiality of data gathered in this investigation: your identity will not be made public. To protect your anonymity you will receive a participant identification number. You will receive this number by email and will be asked to enter this number when you complete the online questionnaires. We will not ask for any identifying information in the questionnaires. A file matching your email address to your participant identification number will be kept for the duration of the study, and will be destroyed upon completion of the study. All other data will be securely stored for 5 years, and will then be destroyed. A thesis is a public document and will be available through the UC Library.

The project is being carried out as a requirement of a Master of Psychology by Siobhan Hayde under the supervision of Associate Professor Roeline Kuijer who can be contacted at roeline.kuijer@canterbury.ac.nz she will be pleased to discuss any concerns you may have about participation in the project.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee, and participants should address any complaints to The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz).

If you agree to participate in the study, you are asked follow the given link to the online questionnaire, enter the given ID number provided in this email then read the consent form and indicate your consent by answering yes. Once you do you will be able to proceed onto the questionnaire.

Siobhan Hayde

Support Services

If after completing the questionnaire you are concerned about health and well-being issues or you experience distress and want to talk to someone, we suggest that you contact your general practitioner (GP) or phone on of the helplines listed below.

- Healthline (0800 611 116) for free health advice 24 hours a day, seven days a week.
- Lifeline (0800 543 354) a free counselling service 24 hours a day, seven days a week.

Alternatively we suggest the following Inflammatory Bowel Disease Support groups.

- Crohn's and Colitis New Zealand (crohnsandcolitis.org.nz)
- IBD NZ (www.facebook.com/Crohnscolitisnz)

Appendix D

Consent Form



Department of Psychology
Telephone: +64 3 [Your phone number]
Email: siobhan.hayde@pg.canterbury.ac.nz

In Sickness and in Health: Social Support and Inflammatory Bowel Disease Consent Form for participants

I have been given a full explanation of this project and have had the opportunity to ask questions.

I understand what is required of me if I agree to take part in the research.

I understand that participation is voluntary and that I may withdraw at any time without penalty until one month after submitting my questionnaire. Withdrawal of participation will also include the withdrawal of any information I have provided.

I understand that any information or opinions I provide will be kept confidential to the researchers and that any published or reported results will not identify the participants. I understand that a thesis is a public document and will be available through the UC Library.

I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.

I understand the risks associated with taking part and how they will be managed.

I understand that I am able to receive a report on the findings of the study by contacting the researcher at the conclusion of the project.

I understand that I can contact the researcher Siobhan Hayde (siobhan.hayde@pg.canterbury.ac.nz) or supervisor Roeline Kuijer (roeline.kuijer@canterbury.ac.nz) for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz)

By selecting yes below, I agree to participate in this research project.

Siobhan Hayde

Appendix E

Social Support and Inflammatory Bowel Disease Questionnaire

Q118 Please carefully read the following consent form and select your answer at the bottom. If you have any questions please refer first to the information sheet then feel free to email Siobhan any questions.

Q52 Consent Form

In Sickness and in Health: Social Support and Inflammatory Bowel Disease Consent Form for participants

I have been given a full explanation of this project and have had the opportunity to ask questions.

I understand what is required of me if I agree to take part in the research.

I understand that participation is voluntary and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided.

I understand that any information or opinions I provide will be kept confidential to the researchers and that any published or reported results will not identify the participants.

I understand that a thesis is a public document and will be available through the UC Library.

I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.

I understand the risks associated with taking part and how they will be managed.

I understand that I am able to receive a report on the findings of the study by contacting the researcher at the conclusion of the project.

I understand that I can contact the researcher Siobhan Hayde (siobhan.hayde@pg.canterbury.ac.nz) or supervisor Roeline Kuijer (roeline.kuijer@canterbury.ac.nz) for further information.

If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz)

By selecting yes below, I agree to participate in this research project.

☐ Yes (1)

☐ No (2)

Q95 Thank you for your interest in our study! We are looking for participants who are willing to complete two questionnaires, three months apart, on their inflammatory bowel disease activity (IBD) and their experience of social support. Those who complete both questionnaires will go into the draw to win an Apple Ipad mini.

Q96 INSTRUCTIONS There are no 'correct' or 'incorrect' answers, we are interested in how you feel and what you think. Try not to over think your answers, your immediate reaction to each question will probably be more accurate than a long thought-out response. If you are unsure about how to answer please give the best answer you can.

Q117 Please enter the identification number (ID) emailed to you.

Q97 Please tick the appropriate answer or fill in the box provided.

Q1 What is your year of birth?

Q17 Are you?

- ☐ Male (1)
- ☐ Female (2)
- ☐ Unspecified (3)

Q2 What is your diagnosis? (if neither of these apply, please exit the questionnaire)

- ☐ Crohn's Disease (1)
- ☐ Ulcerative Colitis (2)

Q80 Which ethnic group do you belong to? (more than one answer possible)

- ☐ New Zealand European (1)
- ☐ Maori (2)
- ☐ Samoan (3)
- ☐ Cook Island Maori (4)
- ☐ Tongan (5)
- ☐ Niuean (6)
- ☐ Chinese (7)
- ☐ Indian (8)
- ☐ Other (such as Dutch, Japanese, Tokelauan) please state (9) _____

Q3 How long ago were you diagnosed

- ☐ 1 month - 6 months ago (1)
- ☐ 6 months - 1 year ago (2)
- ☐ 1 year - 2 years ago (3)
- ☐ 2 years - 5 years ago (4)
- ☐ 5 years - 10 years ago (5)
- ☐ 10 + years ago (6)

Q94 Are you currently suffering from a mental health disorder, other than depression?

- ☐ Yes (1)
- ☐ No (2)

Q117 Do you have a current diagnosis of Major Depressive Disorder (Depression)?

- ☐ Yes (1)
- ☐ No (2)

Q98 The following questions are for those with a diagnosis of Crohn's disease only, please skip if your diagnosis is Colitis. These questions are about the severity and activity your illness and the impact this has on your life. The following questions ask for detailed information about the physical symptoms of Crohn's disease, it is completely understandable if you don't feel comfortable sharing this personal information and decide to withdraw your participation from the study.

Q4 How is your general well-being?

- ☐ Excellent (1)
- ☐ Very good (2)
- ☐ Good (3)
- ☐ Fair (4)
- ☐ Poor (5)

Q5 Rate your level of abdominal pain.

- ☐ None (1)
- ☐ Mild (2)
- ☐ Moderate (3)
- ☐ Severe (4)

Q6 On average how many liquid stools per day in the last month?

- ☐ 0 (1)
- ☐ 1 (2)
- ☐ 2 (3)
- ☐ 3 (4)
- ☐ 4 (5)
- ☐ 5 (6)
- ☐ 6+ (7)

Q7 Some people with Crohn's disease develop an abdominal mass, which is an abnormal growth which occurs in the stomach. If you suffer from this rate it's presence.

- ☐ Fine (1)
- ☐ Dubious (2)
- ☐ Definite (3)
- ☐ Definite and tender (4)
- ☐ I don't have an abdominal mass (5)

Q8 Do you experience any complications currently?

- ☐ None (1)
- ☐ Arthralgia (joint pain) (2)
- ☐ Uveitis (inflammation of the uvea/eye) (3)
- ☐ Erythema nodosum (inflammation causing red lumps on the legs) (4)
- ☐ Aphthous ulcers (mouth ulcers) (5)
- ☐ Pyoderma gangrenosum (deep ulcers on legs) (6)
- ☐ Anal fissure (tear in anus) (7)
- ☐ New fistula (abnormal connection between an organ, vessel or intestine and another structure) (8)
- ☐ Abscess (buildup of pus) (9)

Q99 The following questions are for those with a diagnosis of Colitis only, please skip if your diagnosis is Crohn's disease. These questions are about the severity and activity your illness and the impact this has on your life. The following questions ask for detailed information about the physical symptoms of Colitis it is completely understandable if you don't feel comfortable sharing this personal information and decide to withdraw your participation from the study.

Q9 On average how many times a day do you move your bowel over the last month?

Q10 On average how many times a night do you move your bowel over the last month?

Q11 How urgent is defecation (bowel movement)

- ☐ Hurry (1)
- ☐ Immediately (2)
- ☐ Incontinence (3)
- ☐ Other (4) _____

Q12 How often is there blood in the stool?

- ☐ Never (1)
- ☐ Rarely (2)
- ☐ Occasionally (3)
- ☐ Usually (4)

Q13 How is your general well-being?

- ☐ Excellent (1)
- ☐ Very good (2)
- ☐ Good (3)
- ☐ Fair (4)
- ☐ Poor (5)

Q14 The following questions are about how your illness may be affecting you physically and emotionally. Over the last two weeks have you been bothered by any of the following problems?

Q15 Little interest or pleasure in doing things

- ☐ Not at all (1)
- ☐ Several days (2)
- ☐ More than half the days (3)
- ☐ Nearly every day (4)

Q18 Feeling down, depressed, hopeless

- ☐ Not at all (1)
- ☐ Several days (2)
- ☐ More than half the days (3)
- ☐ Nearly every day (4)

Q19 Trouble falling or staying asleep, or sleeping too much

- ☐ Not at all (1)
- ☐ Several days (2)
- ☐ More than half the days (3)
- ☐ Nearly every day (4)

Q20 Feeling tired or having little energy

- ☐ Not at all (1)
- ☐ Several days (2)
- ☐ More than half the days (3)
- ☐ Nearly every day (4)

Q21 Poor appetite or overeating

- ☐ Not at all (1)
- ☐ Several days (2)
- ☐ More than half the days (3)
- ☐ Nearly every day (4)

Q22 Feeling bad about yourself - or that you are a failure or have let yourself or your family down

- ☐ Not at all (1)
- ☐ Several days (2)
- ☐ More than half the days (3)
- ☐ Nearly every day (4)

Q23 Trouble concentrating on things, such as reading the newspaper or watching television

- ☐ Not at all (1)
- ☐ Several days (2)
- ☐ More than half the days (3)
- ☐ Nearly every day (4)

Q24 Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual

- ☐ Not at all (1)
- ☐ Several days (2)
- ☐ More than half the days (3)
- ☐ Nearly every day (4)

Q25 Thoughts that you would be better off dead, or of hurting yourself

- ☐ Not at all (1)
- ☐ Several days (2)
- ☐ More than half the days (3)
- ☐ Nearly every day (4)

Q26 The following question are about possible physical or emotional symptoms you may be experiencing. Please read each statement and choose an answer which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Try not spend too much time on any statement.

Q28 I found it hard to wind down

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q29 I was aware of dryness of my mouth

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q30 I couldn't seem to experience any positive feeling at all

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q31 I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q32 I found it difficult to work up the initiative to do things

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q33 I tended to over-react to situations

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q34 I experienced trembling (eg, in the hands)

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q35 I felt that I was using a lot of nervous energy

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q36 I was worried about situations in which I might panic and make a fool of myself

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q37 I felt that I had nothing to look forward to

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q38 I found myself getting agitated

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q39 I found it difficult to relax

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q40 I felt down-hearted and blue

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q41 I was intolerant of anything that kept me from getting on with what I was doing

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q42 I felt close to panic

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q43 I was unable to become enthusiastic about anything

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q44 I felt I wasn't worth much as a person

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q45 I felt I was rather touchy

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q46 I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q47 I felt scared without any good reason

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q48 I felt that life was meaningless

- ☐ Never (1)
- ☐ Sometimes (2)
- ☐ Often (3)
- ☐ Almost always (4)

Q49 The following questions are about the social support you received during the past month. If you have a spouse or partner please complete these questions with your partner in mind. If you are not in such a relationship please complete these questions with the most important adult person in your life in mind. I receive social support from,

- ☐ Spouse/partner (1)
- ☐ Mother (2)
- ☐ Father (3)
- ☐ Sister (4)
- ☐ Brother (5)
- ☐ Daughter (6)
- ☐ Son (7)
- ☐ Friend (8)
- ☐ Neighbor (9)
- ☐ Other (10) _____

Q50 Were you able to trust, talk to frankly, and share your feelings with this person?

- ☐ 1 (not at all) (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (very much) (7)

Q51 Were you able to lean on and turn to this person

- ☐ 1 (very much) (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (very much) (7)

Q53 Did he/she give you practical help

- ☐ 1 (not at all) (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (very much) (7)

Q54 Did you spend time with him/her socially

- ☐ 1 (not at all) (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (very much) (7)

Q55 Did he/she comfort you when you were feeling down

- ☐ 1 (not at all) (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (very much) (7)

Q56 Did this person show you that he/she appreciated you

- ☐ 1 (not at all) (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (very much) (7)

Q57 Did this person offer suggestions or ideas as solutions to things that bothered you

- ☐ 1 (not at all) (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (very much) (7)

Q58 All things considered, how satisfied were you with the support and help you received from this person

- ☐ 1 (not at all) (1)
- ☐ 2 (2)
- ☐ 3 (3)
- ☐ 4 (4)
- ☐ 5 (5)
- ☐ 6 (6)
- ☐ 7 (very much) (7)

Q61 Just like the last set, the following questions are about the social support you received during the past month. Please use the same person as you did in the previous questions. The following statements focus on the way your partner deals with the fact that you are ill. Please indicate to what extent your partner does or does not act in the ways described. My partner.....acts in this way.

Q59 My support person tries to discuss it with me openly

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q62 With and excuse, my support person tries to persuade me to follow the doctor's instructions

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q63 My support person asks me how I feel

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q64 When something bothers me, my support person tries to discuss the problem

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q65 My support person tries to hide his or hers worries about me

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q66 My support person tries to act as if nothing is the matter

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q67 My support person gives in when I make an issues of something

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q68 My support person waves my worries aside

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q69 My support person does everything to prevent me from thinking about my disease

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q70 My support person can't endure me being concerned and acts as if he/she doesn't notice my worries

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q71 My support person takes over as much of my work as possible

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q72 My support person treats me like a baby

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q73 My support person continuously keeps an eye on me

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q74 My support person takes care that I follow the doctors instructions

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q75 My support person is full of understanding towards me

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q76 My support person makes me feel that I'm not alone in this

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q77 When it comes down to it, my support person seems to think that he or she can't leave my recovery to me

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q78 When it comes down to it, my support person seems to think that when he or she is not constantly around, I will not follow the doctor's instructions

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q79 When it comes down to it, my support person seems to think I don't know what's right for me

- ☐ never (1)
- ☐ seldom (2)
- ☐ now and then (3)
- ☐ quite often (4)
- ☐ very often (5)

Q100 The following questions are about the social support you receive in GENERAL from your support network. When answering these questions please think about the support you receive from not only your 'support person' but from your friends, family, community etc.

Q82 There is a special person who is around when I am in need

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q83 There is a special person with whom I can share my joys and sorrows

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q84 My family really tries to help me

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q85 I get the emotional help and support I need from my family

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q86 I have a special person who is a real source of comfort to me

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q87 My friends really try to help me

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q88 I can count on my friends when things go wrong

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q89 I can talk about my problems with my family

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q90 I have friends with whom I can share my joys and sorrows

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q91 There is a special person in my life who cares about my feelings

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q92 My family is willing to help me make decisions

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q93 I can talk about my problems with my friends

- ☐ Very strongly disagree (1)
- ☐ Strongly disagree (2)
- ☐ Mildly disagree (3)
- ☐ Neutral (4)
- ☐ Mildly agree (5)
- ☐ Strongly agree (6)
- ☐ Very strongly agree (7)

Q81 The following question is about how you would currently rate your quality of life. Please imagine a ladder with steps numbered from zero at the bottom to 10 at the top. The top of the ladder represents the best possible life for you and the bottom of the ladder represents the worst possible life for you. On which step of the ladder would you say you personally feel you stand at this time?

- ☐ 0 (1)
- ☐ 1 (2)
- ☐ 2 (3)
- ☐ 3 (4)
- ☐ 4 (5)
- ☐ 5 (6)
- ☐ 6 (7)
- ☐ 7 (8)
- ☐ 8 (9)
- ☐ 9 (10)
- ☐ 10 (11)

Q101 The following questions ask about your feelings and thoughts during THE PAST MONTH. In each question, you will be asked HOW OFTEN you felt or thought a certain way. Although some of the questions are similar, there are small differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the exact number of times you felt a particular way, but tell me the answer that in general seems the best. For each statement, please tell me if you have had these thoughts or feelings: never, almost never, sometimes, fairly often, or very often.

Q102 In the past month, how often have you been upset because of something that happened unexpectedly?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q103 In the past month, how often have you felt unable to control the important things in your life?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q104 In the past month, how often have you felt nervous or stressed?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q105 In the past month, how often have you felt confident about your ability to handle personal problems?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q106 In the past month, how often have you felt that things were going your way?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q107 In the past month, how often have you found that you could not cope with all the things you had to do?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q108 In the past month, how often have you been able to control irritations in your life?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q109 In the past month, how often have you felt that you were on top of things?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q110 In the past month, how often have you been angry because of things that happened that were outside of your control?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q111 In the past month, how often have you felt that difficulties were piling up so high that you could not overcome them?

- ☐ Never (1)
- ☐ Almost Never (2)
- ☐ Sometimes (3)
- ☐ Fairly Often (4)
- ☐ Very Often (5)

Q112 This is the end of the questionnaire, thank you very much for your participation. We will email you in 3 months time to complete the survey again.

Q113 The winners of the Ipad Mini and the \$150 Westfield will be notified by email. Would you like to participate in the draw?

- ☐ Yes (1)
- ☐ No (2)

Q114 Would you like to receive a summary of the findings of the study?

☐ Yes (1)

☐ No (2)

Appendix F

If after completing the questionnaire you are concerned about health and well-being issues or you experience distress and want to talk to someone, we suggest that you contact your general practitioner (GP) or phone on of the helplines listed below

- Healthline (0800 611 116) for free health advice 24 hours a day, seven days a week
- Lifeline (0800 543 354) a free counseling service 24 hours a day, seven days a week.

Alternatively we suggest the following Inflammatory Bowel Disease Support groups.

- Crohn's and Colitis New Zealand (crohnsandcolitis.org.nz)
- IBD NZ (www.facebook.com/Crohnscolitisnz)

